A I D S TREATMENT N E W S

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The global AIDS epidemic is still getting worse. There have been successes, however, and many countries are at a critical stage where they could prevent a major epidemic if they act now; while some are beginning to do so, others are not. Overall there has been a big growth in commitment by governments of rich countries and developing countries alike, though financially the current effort is only about half of what is needed. Stigma remains a major obstacle to stopping the spread of HIV and getting those infected diagnosed and treated.

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These expert guidelines for treating neuropathic pain are particularly important, since most of the treatments are off label -- meaning that they have been approved by the FDA but not for this particular purpose. These guidelines will help educate doctors about what treatments are best, and should also help in getting insurance reimbursement for care that clearly represents expert consensus but is not in the official labeling at this time.

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AIDS Treatment News

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Statement of Purpose:
AIDS Treatment News reports on experimental and standard treatments, especially those available now. We interview physicians, scientists, other health professionals, and persons with AIDS or HIV; we also collect information from meetings and conferences, medical journals, and computer databases. Long-term survivors have usually tried many different treatments, and found combinations that work for them. *AIDS Treatment News* does not recommend particular therapies, but seeks to increase the options available.

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different way to sell information or help raise funds online. A system designed to encourage sharing allows subscribers or donors to use parts of their subscription to create new subscriptions for others, without the publisher's involvement -- eliminating registration, reducing transaction costs, encouraging larger subscriptions or donations, and creating opportunities for bringing people together around an idea, purpose, or cause.

World AIDS $4.7 Billion -- WorldCom $35 Billion

by John S. James

A month ago newspapers reported a huge bankruptcy settlement that wiped out about $35 billion in debt for one corporation, the notorious WorldCom.

"A federal bankruptcy judge yesterday gave his approval to a plan by telecommunications giant WorldCom and its creditors to exit bankruptcy by the end of the year. The decision wipes out in one stroke nearly $35 billion in debt, and positions the scandal-plagued company to again become a viable business and a formidable player in the intensely competitive industry." *Philadelphia Inquirer*, November 1, 2003.

The total worldwide spending for AIDS prevention, treatment, and care

was $4.7 billion in 2002, the latest year for which figures are available (UNAIDS, *Report on the State of HIV/AIDS Financing*, June 2003).

The comparison speaks for itself -- $4.7 billion to control an epidemic killing 3,000,000 people this year, vs. $35 billion in debt restructuring to rehabilitate a single company heavily involved in one of the biggest scams in history.

The failure to respond to AIDS is a human problem, not a fact of nature. All of us can do our part to demand political will. The basic commitment is to insist on workable arrangements instead of settling for something less. WorldCom apparently has effective political consensus and cooperation on a viable path forward. But AIDS still does not.

UNAIDS Report for 2003: Most Deaths and New Infections Ever; Some Good News

Three million people died of AIDS this year compared with 2.7 million last year, and five million were newly infected -- both more than ever before, according *AIDS Epidemic Update: December 2003*, compiled and published by UNAIDS, the United Nations Joint Programme on HIV/AIDS. Forty million people are now living with HIV, up slightly from last year.

There is good news from a number of individual countries, as well as increased commitment from many governments, and increased total resources worldwide devoted to the epidemic. Some prevention programs have worked well. But many countries are at a critical stage where they could abort a major epidemic if they act now. Unfortunately some of their governments are still not serious about AIDS.

AIDS Epidemic Update: December 2003 is available at:
http://www.unaids.org

A few situations, among hundreds of others:

* Swaziland, in Southern Africa, shows how fast HIV can spread. In 2002 almost 39% of the entire adult population age 15-49 had HIV. Ten years before it was 4%. (Imagine what this means for Eastern Europe, many parts of Asia, and other places where governments are not dealing with an early epidemic that could still be stopped, if only people mobilize in time.)

* In Africa, fewer than 2% of those who need treatment now can get it. In heavily affected countries, only about 1% of women have access to services for prevention of mother-to-child transmission.

* In many African countries, HIV prevalence seems to be stabilizing at a high level -- but this is not really good news. The reason the percentage infected is not higher is that more people are dying.

* In the U.S., about half of the 40,000 new infections this year are of African-Americans (who make up 12% of the population) -- often women who avoid high-risk behavior themselves but get HIV from men who are secretly having risky sex or sharing needles -- just one of many

illustrations of how stigma and discrimination make AIDS control more difficult.

* Successes include Kampala, Uganda (about 8% of pregnant women now have HIV, an indicator of prevalence in the general adult population -- a "remarkable feat" according to the report). No other country has done as well, although big drops have also occurred in Ethiopia and Rwanda.

* "Globally, the AIDS response is moving into a new phase. Political commitment has grown stronger, grass-roots mobilization is becoming more dynamic, funding is increasing, treatment programmes are shifting into gear, and prevention efforts are being expanded." (*AIDS Epidemic Update, December 2003*).

Total public and private global spending on AIDS prevention, treatment, and care is now about $4.7 billion dollars ($4,700,000,000) a year, compared to a need of $10 billion -- better than before, but scandalously low for an epidemic killing 3,000,000 people per year and likely to kill tens of millions more.

* As programs scale up, another critical shortage is trained personnel. HIV treatment is needed now to keep medical and other trained people alive. Also, despite critical shortages, thousands of nurses in Africa are now unemployed due to caps on spending for public services.

Facts like these hint at what individuals and organizations can do. Many of the problems are local, and can only be handled by those directly involved. But many others (especially the lack of resources) are global. And many problems in the developing world originate in the U.S. and other rich countries.

New Neuropathy Treatment Guidelines

by John S. James

An expert panel has recommended five different kinds of drugs that are suitable for treating neuropathy pain in some patients. The review and recommendations were published in the November issue of *Archives of Neurology*(1). These guidelines mention HIV but are not HIV-specific. They are available free on the Web (at least when we checked on December 1, 2003) at:
http://archneur.ama-assn.org/cgi/content/full/60/11/1524

From the article:

"First-line Medications. The efficacy of gabapentin, the 5% lidocaine patch, opioid analgesics, tramadol hydrochloride, and tricyclic antidepressants (TCAs) has been consistently demonstrated in multiple randomized controlled trials. Each one can be used as an initial treatment for neuropathic pain in certain clinical circumstances. Opioid analgesics and TCAs generally require greater caution than the other options. For each of these 5 medications, brief reviews of the relevant randomized clinical trials and specific treatment recommendations follow. Treatment recommendations are summarized in Table 2."

Not recommended but sometimes used are NSAIDS; many experts

believe they are not effective for this kind of pain.

(However, *AIDS Treatment News* has heard anecdotal reports of relief with Voltaren Emulgel, an NSAID in a topical formulation. The topical form is not sold in the U.S., but may be available from Internet pharmacies for under $20. See our 1999 article at: http://www.aids.org/atn/a-321-01.html)

The same issue of *Archives of Neurology* also has an article on surgical treatment for neuropathy pain(2), and an editorial(3).

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2. Giller CA. The Neurosurgical Treatment of Pain. *Archives of Neurology.* November 2003; volume 60, number 11, pages 1537-1540.

3. Rosenberg RN. Pain 2003. *Archives of Neurology.* November 2003; volume 60, number 11, page 1520.

Revised U.S. Adult and Adolescent Antiretroviral Treatment Guidelines; Also Revised Pediatric Guidelines

by John S. James

Small but important revisions to the U.S. Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents were published in a revised document on November 10, 2003. The latest HIV treatment guidelines are always available at:
http://www.aidsinfo.nih.gov/guidelines/

The revised guidelines include warnings against two three-drug NRTI combinations that should never be used as a triple regimen (abacavir + tenofovir + lamivudine, and tenofovir + didanosine + lamivudine), because these regimens failed to control viral load in treatment-naive volunteers in recent clinical trials, leading to development of viral resistance in some patients. The problem with these regimens is well known -- but unless the warning is in the guidelines, some physicians with little HIV experience may make a mistake.

The warning against combining d4T + ddI (stavudine plus didanosine) due to risk of toxicities now clearly applies not only in pregnancy but to anyone (unless the benefits outweigh the risks for a particular patient). The

previous edition of the guidelines had been criticized for being ambiguous on this.

The revised guidelines warn against combining atazanavir + indinavir (possible worse hyperbilirubinemia), and FTC + 3TC (similar resistance profile, without additional benefit).

And they also include additional information on T-20 (enfuvirtide).

Atazanavir and FTC have been added to the guidelines as potential alternative drugs in certain regimens. (The new guidelines also make it clear that "alternative" recommendations can be the preferred treatment for some patients.)

This edition includes a helpful "What's New in This Document?" section just after the cover page.

Patients who want to check to see how their treatment compares should note that much of the information is in the tables at the end of the document. Remember that HIV-expert physicians may have good reason for not following the guidelines in some cases.

Pediatric HIV Guidelines Revised

A revised *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection* was published November 26, 2003, by the U.S. Department of Health and Human Services. It is also available at the U.S. government Web site for official HIV treatment and related guidelines:
http://www.aidsinfo.nih.gov/guidelines/

AIDS Treatment News: Changes Next Year

by John S. James

At *AIDS Treatment News* we are considering two long-term changes, and want to share our thinking with our readers. You can send comments to us at: aidsnews@aidsnews.org.

First, we must change because our traditional business model has gone away. For almost 15 years *AIDS Treatment News* was supported mainly by individual subscriptions. But today many of our subscribers are on disability or otherwise unable to pay, so we provide the newsletter without cost to old and new subscribers (including over 200 prisoners). *AIDS Treatment News* is not currently set up as a non-profit, so we pay for the free subscriptions out of pocket without funding. We do not accept grants or contributions from pharmaceutical companies or others whose products we might cover, although they can subscribe.

Business subscriptions now account for most of our income, which concerns us. Today the pharmaceutical industry funds almost all AIDS treatment publications. So far this system has worked better than we would have expected, but that could change any time. If the community loses its independent publications it will be in trouble. *AIDS Treatment News* must change its business model, or slide into increasing dependence on industry.

Second, during the next year we will begin reporting primarily online -- while still making print copies available, because many people want or need them. Online reporting will allow us to cover breaking news and

other stories we now miss because they are history by the time our print newsletter reaches subscribers. Online publication will also allows us to update articles when necessary (we plan to publish a record of the changes).

We are considering three business models to replace the one that no longer exists. Starting with the best, they are:

1. *AIDS Treatment News* would be housed within a nonprofit, and all online distribution would be free. The print edition would then be self-supporting, especially if funding could be found to pay for prisoners and others who need free copies. We might outsource the printing and distribution to a separate organization, so that we could focus on the reporting. We are seeking funding for the online edition, and for those who need free print subscriptions.

2. The second choice is to continue the current business model, but find support for the free print subscriptions.

3. The third choice is to charge a small fee for subscriptions online.

Selling information online has been notoriously difficult for many who have tried it. While exploring the possibility, we devised a radically new method (called Subscriptions to Share) that we think could work for selling subscriptions, and also for online fundraising. But we want to focus on AIDS, not on developing business or fundraising methods -- and our online newsletter should be free instead of low cost. Subscriptions to Share remains a possibility, however. We summarized it below in the hope that it will be useful to others.

Subscriptions to Share: New Way to Sell Content or Help Fundraising Online

by John S. James

While exploring future options for *AIDS Treatment News* I found a flexible way to sell information or help raise funds online. While *AIDS Treatment News* may not use it because we want to make our information free, I'm publishing this summary to help small publications and other projects that might benefit. For the full article see the Web link below.

The Need

One of the biggest obstacles to small publications today is the difficulty of charging low prices for online content. Thousands of people now make a living selling knick-knacks on eBay because they can reach a global market through the Internet. But few writers and editors can make an independent living that way (unless they serve a high-priced, usually corporate market) -- largely because the transaction cost and inconvenience of charging any money at all will greatly reduce readership, probably by 90% or more. Even requiring free registration at a Web site can seriously reduce its use.

The world would be a better place if thousands of individuals and small organizations could make a living writing, editing, or publishing online,

charging maybe 25 or 50 cents per newsletter issue, or per article downloaded. I believe the publishing industry has missed opportunities to do this, because of its obsession with preventing subscribers from sharing proprietary information. Designing systems to encourage sharing gives a very different perspective.

Subscriptions that Propagate

We will show how to sell subscriptions online with no registration at all. The publisher does not need a user name, email address, or any other contact information for subscribers. The reason is that all subscribers can break off pieces of their subscription and sell or donate them as totally new subscriptions of whatever size, without the publisher's involvement. These new subscriptions can also reproduce -- and so on to any depth. While the publisher does not need to do anything in this reselling or giving away of his or her information, the publisher does get paid for it -- and can control it, since the publisher's server keeps track of all subscriptions and handles fulfillment.

For example, the publisher can sell one large subscription to a public library, which can then give away hundreds of tiny subscriptions (access to one download, or a handful of them) for clients to use anywhere. Or an individual can buy a subscription and offer dozens of small subscription grants, worth a few dollars each, to anyone anywhere in the world who explains in two or three sentences how they will use it to support a particular cause -- bringing people together around that cause, and putting it on the table for public discussion.

Publishers do not need to contact subscribers when articles come out, since anyone can get notices and summaries through open list serves.

Less obvious consequences of Subscriptions to Share include:

* A single subscription can give access to hundreds of different publishers -- and hundreds of different charities as well, automatically keeping tax records and printing documentation on request.

* A subscription can sell digital tickets to fundraising or commercial events (if the event sponsor offers the service and the subscription owner allows it). These digital tickets (like the subscriptions themselves) are small codes, as short as four characters long, that can easily be written down or given over the phone, but are almost impossible to guess. At the event they are scanned or typed in. A single digital ticket can admit one person or any number, whether they arrive together or separately. If payment is through an existing subscription no financial transfer is necessary. This means that in one minute online you could make reservations and buy a single ticket for a dozen people arriving in several groups, phone the code to each group, and meet inside the theater. If someone cannot make it you can call somebody else and give them the code -- no need to resell any ticket, nor arrange to meet outside.

* Corporations or others that want to distribute bulk copies of an article (either online or in print) can buy a